
Death with Dignity: There's Plenty More that We Can Do

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The medical profession has seen an accelerated interest in end of life decision making and terminal care. The growing need for attention in these area requires more of the art of medicine - the human and compassionate side of medicine as opposed to the high technology side.

Everyone knows or at least has heard the facts and statistics. The population of the United States and most other "developed" nations is aging. The group eighty-five and older is growing at an unprecedented rate. Control of certain infectious diseases and public health measures over the last half century are largely responsible for this demographic shift.

The challenge to the medical profession now and in the immediate future is to better respond to the needs of an elderly population with chronic debilitating and endstage conditions. The financial and societal implications of this challenge were addressed by Dr Patricia Blanchette in the April 1995 issue of the *Hawaii Medical Journal*. The points raised in that article are even more compelling a year and a half later. The frail elderly with chronic and terminal medical conditions can be cared for in ways that are both fiscally sound and personally satisfying, tailored to meet the individual's needs.

For physicians to manage these chronic problems well requires a change in approach. The traditional 10 to 15 minute office visit is not adequate to meet the needs of this population. The scope of care is expanded to include the office, hospital, nursing home, hospice, and most importantly, the home. The physician becomes less the autonomous decision maker and more a team member, communicating with various professional disciplines and caregivers. The ability to be a good team member and to balance the expertise of different people is a crucial part of caring for people with chronic and terminal conditions.

Many physicians, some may argue the majority, do not handle this end of the continuum of life that well. There are many reasons for this. There is real paucity of formal medical education in the areas of death and dying, not to mention the management of chronic conditions generally. The advent of so much new technology so rapidly and the emphasis on this in medical education leads many physicians to feel that they should be able to fix anything. High

technology should be used to the very end and if this fails, it is time to walk away. Residency programs are great in teaching how to run an intensive care unit, but what happens beyond the hospital door remains, for many, a big mystery. Even in an office practice, once a diagnosis of a chronic incurable condition is made, frequently the physician-patient interaction stops at this point. An example: a patient, after a complete and thorough workup, is diagnosed with Alzheimers Disease; the family is told this, given a couple of pamphlets, but no follow up is scheduled because "there is nothing more that we can do." Experience in working with elderly people with chronic and terminal conditions shows that the point where "there is nothing more that we can do" is actually where the real work begins.

Communication and availability are crucial to successfully take care of a terminally ill person. It is important for the physician to communicate clearly with the patient and family what to expect and what can be done. Often the patient is told "I'm sorry, you have (for instance) cancer, we have no treatment to offer." A better approach is to say "I'm sorry, you have a condition that we can't cure. However, there are many things that we can continue to do to make sure that you can be comfortable and pain free."

There are many issues to address at the beginning as well as during the course of a terminal illness. First, if no previous discussion has occurred, an active discussion about life sustaining measures needs to be addressed. The general public usually has little understanding of what the implications of resuscitation, hydration, and tube feeding are. Asking only "do you want us to do everything if an emergency occurs?" will not lead to an informed response. Giving the family solid information about the futility of resuscitation and tube feeding in such conditions will permit much better decision making. Obviously it is much better to face these issues early rather than when the crisis occurred. All too often patients with advanced metastatic cancer end up in an intensive care unit being intubated and resuscitated because no one had discussed the options beforehand.

The case of a patient with advanced Alzheimers Disease illustrates this well. Once the patient starts to develop dysphagia, families are confronted with having to decide whether to tube feed or not. One approach is to explain to the family that artificial feeding will not reverse the underlying process and in fact will increase the likelihood of suffering by interfering with the natural process and in fact will increase the likelihood of suffering by interfering with the natural process of death. Many families have the misconception that without artificial feeding or hydration, the patient will experience a slow, painful death. Explain that the opposite is true and that the patient will have a comfortable and dignified death without artificial support. Often families do not want to pursue aggressive measures but are afraid to speak out. When the physician speaks to these issues directly, providing more guidance and education, this puts the family more at ease to make choices. Families are already stressed: they need more direction from the physician than being asked "do

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you want this treatment or not?"

Most people are taken care of in the home; patients and families generally prefer this to institutionalization. Making use of community resources during this period is great help to both the family and physician. A hospice program is extremely beneficial. Often hospice is equated with cancer care; however the same philosophy applies to any endstage condition, such as advanced dementia or Parkinson's disease. A hospice can provide skilled nursing services; nurses aid services, respite care, social services as well as coverage for medications and certain supplies. Nursing services are especially helpful in working with the physician to modulate medications for pain.

Patients at this point rarely fear death itself. They fear more the potential of having pain and suffering during the dying process. Unfortunately, many patients do not have these fears addressed and do not receive the necessary medications to relieve their pain. A recent article in the *New England Journal of Medicine* describes this well. Adequate treatment of pain in terminal conditions is not given sufficient attention for many reasons: lack of education, inappropriate concern about the effects of narcotics to name two. Concern about addiction in a patient with a terminal illness really approaches the absurd.

Depression as a co-morbid condition in a chronic disease and terminal illness is also under recognized and treated. Depressive symptoms are often dismissed as being an accepted part of the condition thus not meriting attention. In many cases an antidepressant can be very beneficial in improving the quality of life and as an adjunct to treating pain.

The following illustrates a "best case scenario." An 80-year-old man with endstage Parkinson's Disease and dementia is cared for at home by his wife and a hired caregiver. The physician makes routine home visits to provide support and guidance in the day to day care. As the disease progresses, the patient develops symptoms of dysphagia. Discussions between the wife and physician on previous occasions have led to the decision not to tube feed or do other aggressive measures. As the dysphagia represents a significant change in the prognosis, a referral to Hospice is made to assist with the terminal care. The physician prescribes liquid morphine to have on hand in the event of respiratory distress probably due to aspiration. Visits are made by both the hospice nurse and the physician to provide additional support. The wife is instructed to give as much morphine as is necessary to relieve the respiratory distress. After several days, the patient passes away quietly at home with the wife during the days that follow. A much preferred passing to what could have happened without adequate preparation: years of meaningless existence in vegetative state with a feeding tube in a nursing home.

The need for this kind of care will only grow in the future. Physicians can and should play such an important part in the care of dying patients. Despite the availability of excellent paraprofessionals, patients and families ultimately look to the physician for real guidance and decision-making. There is so much to do medically during the dying process: aggressive relief of pain, aggressive treatment of depression, aggressive use of community resources. Being at the bedside of a dying patient, if to do nothing else but listen, can be the greatest practice of the art of medicine.

References

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Euthanasia: Murder or Mercy?

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women to find doctors who would perform abortions in those days before *Roe vs. Wade*. Battin saw religious institutions as the right place for people to come. A religious community is the only place whose central focus is the meaning and value of life, and the disturbing fact of death which challenges all claims to meaning and value.

The work of Ralph Mero and others clearly indicates that some of our clergy are hearing the call to respond to those suffering people in need of aid in dying. Such work is to be highly commended and extended by others of us as we are able.

The ultimate goal is to enable every person not carried away by sudden death to make informed choices about what happens to them in the last stages of life. We will not all choose the same way. There must be room for those who choose to live even in the face of frightful pain and suffering and for those who choose an earlier point of death.

The Greeks gave us the word euthanasia. It is a lovely word that means simply, good death. Only if we are given the full legal right to make the choice of how we shall die, and to get the assistance of our physicians in carrying out that choice—for existence to continue by every means possible or for death to take us out of our misery—does the good death, euthanasia, become possible for all of us. It is my hope that every person will be able to have a good death.

Editor's Note:

Ken Phifer now serves as Senior Minister at First Unitarian Universalist Church in Ann Arbor. He received a B.A. in history at Harvard and attended the University of Chicago Divinity School. He served as Scholar in Residence at the Ecumenical Institute for Jewish Christian Studies, as well as teacher, advisor and Minister at several institutions on the mainland. But, Ken Phifer has firm connections to Hawaii: he taught at Mid-Pacific Institute, has lectured at the Pali Unitarian Church and his parents live in Hawaii at Pohai Nani. Mahalo, Ken for sharing your words of compassion with us.

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